CCI Europe's Ukraine Report

February 28, 2023

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SAFER UKRAINE











€262.000 RECEIVED FROM 300 DONATORS



THE TEAM

CCI Europe joined St. Jude Global, other partners in Ukraine, the Polish Society of Pediatric Oncology and Hematology (PSPOH), and an international network of hospitals and governments in creating a **Supporting Action for Emergency Response in Ukraine (SAFER Ukraine)**. SAFER Ukraine is a humanitarian effort launched following the Russian invasion of Ukraine with the mission to aid Ukrainian children with cancer and blood disorders to receive high quality medical care, in Ukraine or abroad, through capacity building and international collaboration.

THE MISSION



INFORM

We make sure all CCI-E's members are updated on a monthly basis. We bring awareness of the SAFER Ukraine role to the public through conferences and publications.



IDENTIFY

We identify in each European country a contact point able to commit to welcome and support Ukrainian families including transportation, lodging, daily needs, and psycho-social needs.



SUPPORT

We continuously support patients and their families who fled Ukraine by providing psychosocial tools and connecting them with local services.



LIASE

We liaise between Ukrainian organisations and CCI Europe's representatives in each country by providing support and resources in case challenges occur.



REUNITE FAMILIES

We facilitate family reunifications in collaboration with the SaferUkraine team, Tabletochki and the respective local member coordinator.



MANAGE

We manage the Ukrainian Emergency Fund in order to be able to finance immediate needs and requests.

UKRAINIAN EMERGENCY FUND

€262.000 donations received from more than 300 donators. As of December 2022, the funds have been distributed as:

€11,000

Reunification and Funeral Costs

€48,000

Expert and Competences Costs

€202.000

Funding available for continuous support



Ukraine Response Overview - The start of an organised evacuation pathway and treatment and care plan: SAFER Ukraine

Right after the war in Ukraine started, CCI Europe joined St. Jude Global, other partners in Ukraine, the Polish Society of Pediatric Oncology and Hematology (PSPOH), and an international network of hospitals and governments in creating a **Supporting Action for Emergency Response in Ukraine** (SAFER Ukraine). SAFER Ukraine is a humanitarian effort launched following the Russian invasion of Ukraine with the mission to aid Ukrainian children with cancer and blood disorders to receive high quality medical care, in Ukraine or abroad, through capacity building and international collaboration.

This broad cooperation with different expertise, but with shared importance and urgency, allowed quick and efficient decisions resulting in impressive support and help.

To date, SAFER Ukraine collaborative facilitated the support for over 1300 patients and their families in 21 countries. The scope of support varies based on the patient and family needs and includes translation of medical records, connecting with clinicians in the countries where families fled war, as well as medical evacuation and patient referral to the long-term care facilities abroad. Most patients are continuing treatment in Poland (>300), Germany (>150), Italy (>150). Spain, France, Czech Republic, Netherlands, Switzerland accepted over 50 patients, followed by Austria, Belgium, Romania, Slovakia, UK, Portugal, Canada and USA accepting 5-20 patients.



Childhood Cancer International – Europe

CCI-Europe, as representative of the pan-European CCI members organisations, is involved in the SAFERUkraine collaboration. CCI-E's contribution is multifaceted:

- Inform all its members and make sure they are getting all up-dates on a weekly basis¹
- Identify among its members for each European country a contact point, able to commit to welcome and support Ukrainian families including transportation, lodging, daily needs, and also psycho-social aspects
- **Liaise** between Ukrainian organisations and CCI-Europe members' representatives in each country, support in case challenges occur
- Support also those patients who fled Ukraine via a route other than SAFERUkraine
- Launch and manage an Ukrainian Emergency Fund in order to be able to finance immediate needs and requests. This Emergency fund is composed of different donations from all kinds and the expenses are controlled by an independent advisory board to ensure full transparency and most efficient management of the funds.
- **Facilitate family reunifications** in collaboration with the SaferUkraine team, Tabletochki and the respective local member coordinator.

The two following working groups were set up within CCI-E:

- a **Task Force**, managing all SAFERUkraine activities as listed above.
- an **Advisory board**, ensuring a disinterested analysis of the Ukrainian Emergency Fund and guaranteeing its full transparency regarding the income and expenditure.

¹ Till end of August 2022, then on a monthly basis

Recurring Meetings and Updates

Since the beginning of the war and the creation of SAFER Ukraine, CCI-E became very involved in supporting the evacuation of children and young adults from hospitals, family reunification efforts, and overall support to its members receiving patients. For these purposes, several meetings were planned and organised.

CCI-E Task Force Meetings

Participants: CCI President, Joao Braganca; CCI-E Chair of Committee, Anita

Kienesberger; CCI-E Vice Chair, Luisa Basset; CCI-E Managing director, Carina Schneider; CCI-E Committee Member expert in cross-border health

care, Anne Goeres

Frequency: Twice a week from March 2022, to the end of October 2022. Weekly from

November 2022

Topics of Updates on the patients evacuation; discussion of members' issues with

discussion/Aims of families/patients in their countries and align possible solutions; updates

meetings: on funding and reunification efforts.

Weekly Updates Meetings with CCI-E Members

Participants: CCI President, Joao Braganca; CCI-E Chair of Committee, Anita

Kienesberger; CCI-E Vice Chair, Luisa Basset; CCI-E Managing director, Carina Schneider; CCI-E Committee Members; Representatives of CCI-E's

members

Frequency: Weekly from March 2022 to end of August 2022, Monthly from September

2022

Topics of Meetings with members to keep them updated about evacuation and

discussion/Aims of reunification efforts; to receive news about their countries and local

issues; to share useful resources and processes to better help Ukrainian

families and patients.

SAFERUkraine coordination meetings

meetings:

meetings:

Participants: SAFER Ukraine's partners meetings

Frequency: Daily in March 2022, reduced to weekly from April 2022, more when need

it

Topics of Regular updates on cases including medical updates and discussion of best

discussion/Aims of location for treatment; logistics and transportation; travels and family

reunifications; updates from country organisations including changes in policies, governmental support available to refugees, and other

information..

Other Meetings

Dissemination Task Force CCI-E Communication Officer and the Ukraine Task Force met on

a regular basis and additionally when needed, to align on communication efforts to CCI-E's members, external and internal

partners (i.e. donors, sponsors, employees, volunteers, etc.)

1-1 meetings CCI-E & Member

organisation

Whenever necessary, CCI-E Task force or a Task force representative met with a member organisation facing challenges with families in their countries. These ranged from housing support, to liaise communication between family and

hospital.

CCI-E Conference in Vienna

(3-5 June 2022)

During the annual CCI-E conference, a particular space was dedicated to the SAFERUkraine topic. Contact persons from the Ukrainian and Polish partners were also invited to present their work and the current efforts in both evacuation and reunification of families with children and young adults with cancer.

Stakeholders meeting in Poland

(7-9 July 2022)

Anne Goeres and Anita Kienesberger attended a two day meeting in Poland and the main aim was to evaluate the past few months of the SAFERUkraine activities, discuss and plan the future of our team and collaboration and the missing links to improve our patients & families support. Another outcome of the meeting was CCI-E's commitment to stay strong partners in SAFERUkraine in order to develop together useful Guidelines, SOP's and tools for

families when they have to leave Ukraine.

SIOP/CCI Conference Barcelona

(28 September – 1 October 2022)

During the annual SIOP/CCI conference, CCI-E presented its involvement and efforts within the SAFERUkraine partnership. This provided insight on the current situation in Ukraine, but also take-aways from the collaboration, and open topics for future

research/developments.

From March 2022 to November 2022, the volunteers and staff members of CCI-Europe participated in more than 130 meetings to coordinate evacuation and family reunifications!

CCI-Europe's know-how: coordination, reunifications, dissemination, and other types of support

Network and key contacts

CCI-E set up a task force as the situation required intense and long-lasting efforts. This taskforce is responsible to communicate with the other SAFERUkraine partners, furthermore it discusses any issue families or patients might have in the host countries, and it's responsible in supervising the funding and reunification efforts. Members of the task force are CCI President, Joao Braganca; CCI-E Chair of Committee, Anita Kienesberger; CCI-E Vice Chair, Luisa Basset; CCI-E Managing director, Carina Schneider; CCI-E Committee Member expert in cross-border health care and communication, Anne Goeres. The taskforce is also in charge of preparing communication and messages to be shared with CCI-E's members, donors, and other stakeholders.

Right after the Ukrainian war started, CCI Europe reached out to its member organisations in Ukraine to inquire about possible needs and how to support them. The immediate response from the Ukrainian member was that to help them, they would need:

- set up a list of European hospitals that could admit Ukrainian children to treat them;
- identify charities that could provide logistic, accommodation, and funding support for the children and carer travelling with them.

CCI-E then reached out to all its member organisations to provide this much needed information.

CCI-E coordinated the communication between Ukraine and CCI-E's members through key point contacts in each country. This mostly included information about hospitals that could accept patients, local NGOs that could support family relocations, in addition to the CCI-E members involved with evacuations and help for families arriving in their countries.

This network of contact was a starting point for the collaboration further developed within SAFERUkraine.

Ukrainian Childhood Cancer Emergency Fund

Ukrainian Childhood Cancer Emergency Fund has been created by CCI-Europe to support the Ukrainian childhood cancer community. CCI-Europe has, in full transparency, allocate funds where they were most needed:

- Travelling: fleeing Ukraine, reuniting families, travelling back home
- Medical: pharmaceutical or medical supplies, drugs, cancer treatment (if not covered by the state's health insurance)
- Housing: pay of rent, hotel, parents house for families of children with cancer from Ukraine (if not covered by local NGO's)
- Daily expenses: food, clothes, hygiene goods
- Translation costs
- Expenses related to funeral costs or repatriation to Ukraine
- Coordination helpline: contact point for all refugee patients and NGOs

The fund is also open for grant requests submitted by CCI-E members: https://ccieurope.eu/funding-ukrainian-childhood-cancer-emergency-fund/ Any grant request will be evaluated by the independent Grant advisory board: this is formed by two people external to the CCI-E's Ukraine task force.

Family Reunifications

CCI-E became the key contact between Tabletochki and the welcoming countries. Initially, the main requests were for family reunification. Often patients are safely evacuated to another hospital but only with one companion – mostly their mothers. Several had left siblings and fathers behind.

Requests for reunification came for single family members or groups (e.g. father plus sibling, or other relatives such as grand-parents). Together with Tabletochki, CCI-E coordinates all the reunification steps: bord crossing (and any document necessary, incl. visas), timely booked travel especially for urgent reunifications, and further support if necessary.

CCI-E successfully supported 26 family reunifications to 8 countries:

Family reunifications by country	
Switzerland	9
France	7
Spain	3
Austria	2
UK	2
Belgium	1
Germany	1
The Netherland	1
	26

Furthermore, CCI-E also coordinated requests of support from already evacuated families. These requests are generally forwarded to a member organisation from the country/city where the family is relocated. The requests of these 25 families included for example support with finding a new/better housing accommodation, psychosocial support, mediation between family and hospital, help in better integrating within the new host country.

Unfortunately, CCI-E also received requests to help with repatriation of patient's body to Ukraine whenever asked for by the family. Thanks to everyone's solidarity, many requests were financed by the hospitals where the patient died. CCI-E contributed financially to one of these three requests.

Other contributions from CCI-E members

CCI-E's members have been very active and involved in creating a receiving network, in supporting and helping families both at arrival and later on. Many volunteers were in direct contact with families to ease their move and further support them navigating both legal and psychological issues that might have arisen.

Members involvement included follow-up on any case where a family in their country needed further support, direct contact with other NGOs and local authorities to better coordinate arrivals and accommodations of Ukrainian families, and share useful tools with other members.

All the resources shared by our members are available on our website: https://ccieurope.eu/ukraine-resources/

Dissemination

In order to disseminate the information about the the <u>Ukrainian Childhood Cancer Emergency Fund</u>, CCI-Europe has started communicating widely.



The main Ukraine <u>landing page</u> was created as soon as the war started. There, all information about CCI-Europe efforts can be found, as well as how our audience can help. We started providing <u>regular updates</u> (also found at the bottom of the Ukraine main landing page) and kept informing the public about our Ukraine endeavours.



CCI-Europe has also developed an "<u>Ukraine Info and Support Material</u>" landing page, where we categorised the collected resources by country who contributed.

CCI-Europe used all its social media channels to disseminate the above mentioned information, and reach out to as many people as possible. The first post about the Fund has reached more than 62.000 people and had almost 300 re-shares.

Working Groups on Psychosocial Care

During the consortium meeting in Poland in July, the need of creating working groups on psychosocial care has been highlighted.

The aim of these working groups is to collect resources and tools, create guidelines, and overall support children with cancer and their families in the transition from Ukraine to another country.

The two groups are working on:

- Psychosocial Services Mapping
- Language and Interpretation Toolbox

The goals of the groups are to collect useful resources or contacts from different countries to then share them with the families who had to be evacuated and therefore provide additional support throughout these times. Together we will decide where these resources can be made accessible for our members and caretakers to support the families in the best possible way.

CCI-E representatives are collaborating in both working groups.

Financial Overview

Donations

The Ukrainian Childhood Cancer Emergency Fund was established at the beginning of March 2022 as the first response to the start of the war.

This Emergency fund is composed of different donations from all over the world and the expenses are controlled by an independent advisory board to ensure full transparency and the most efficient management of the funds.

CCI-E received more than €262,000. - in donations from more than 300 different donors from around the world, including several CCI-E members and industry contributions.

Special thanks to all the donors, in particular the following²:

Fondation Kriibskrank Kanner	Luxembourg	
BARNCANCERFONDEN	Sweden	
Paediatric Cancer Research Foundation	U.S.A.	
ASSOCIATION IMAGINE FOR MARGO	France	
Icelandic Childhood Cancer Parents Organization	Iceland	
dtv Verlagsgesellschaft mbh + Co. KG	Germany	
Drustvo Junaki 3. Nadstropja	Slovenia	
Een Häerz fir kriibskrank Kanner Asbl	Luxembourg	
Österreichische Kinder-Krebs-Hilfe	Austria	
Childhood Cancer Foundation	Ireland	
FLOGA Parents Association of Children with Cancer	Greece	
Eckes-Granini Group GmbH	Germany	
Kinderkrebshilfe Schweiz	Switzerland	
My Shining Star	UK	
Childhood Cancer International	The Netherlands	
SERVIER AFFAIRES MEDICALES	France	
HBLFA Tirol	Austria	
Katherine Susan Moore	Australia	
John and Maeve Greene	U.S.A.	
Association Des Soleils pour Princesse Mimi	Switzerland	
Abhishek Avasthi	Switzerland	
CanCare4Living	Ireland	
SARAWAK CHILDREN'S CANCER SOCIETY	Malaysia	

² List of donors who contributed from €1,000. -

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Reunifications

Reunification costs consisted of travel expenses for family members from Poland (mostly) to the country where the patients have been evacuated. These are one-way tickets, generally flights, for all the family members requesting the support.

Furthermore, at least on one occasion, CCI-E also covered part of the cost for a body repatriation to Ukraine.

Total expenses for these efforts were over €11,000. –

Administrative costs

Administrative costs came up to cover financial fees such as transfer fees or paypal transaction commissions, travel costs for the experts and speakers needed at the CCI-E Vienna Conference and at the SIOP/CCI Barcelona Conference where the SAFER Ukraine project was presented.

Additionally, staff effort in supporting family reunifications, creation of the SAFERUkraine partnership, and continuous updates to members and between partners is also included.

€11,000	€48,000	€202.000
Reunification and Funeral Costs	Expert and Competences Costs	Funding available for continuous support

Final Remarks

CCI-E has a long history in multi-stakeholder collaborations, but no expertise in war conditions and evacuations procedures. The intense collaboration from the start helped to listen, understand and adapt this process. One of the keys of success of the SAFERUkraine, is the clear leadership by one single stakeholder.

Furthermore, SAFERUkraine's success depends on individual commitment of many different people. In this, the support activities worked best in those countries, where specific coordinators were appointed by their organisation to be in charge of the SAFERUkraine mission.

SAFERUkraine is the living proof that the best and quickest success was achieved in those countries where collaboration between hospitals, NGO's, health care professionals and politics worked smoothly and uncomplicated and probably were already well established before. On the other hand, SAFERUkraine highlighted some challenges in each country that are also relevant for CCI-E because it is giving us a better insight on national constraints.

There is no "one size fits all" model for supporting families: organisations work differently in their countries, and so do their health care systems. Another factor that plays into differences is culture. Based on this experience, the importance of psycho-social care for patients and their families was strongly highlighted. Unfortunately, meetings with the medical teams to better align considering logistics and psycho-social matters, came into force only in July.

Such long-lasting emergencies require all parties involved, especially volunteers and people on the field, time, energy, and efforts. Healthy energy-saving became a priority for all the involved parties. Although long-lasting partnerships are not always possible, with SAFERUkraine short and efficient contributions were also very valuable and indispensable.

SAFERUkraine showcased again how important the tight relation with CCI-E's members is. These relations changed positively in the exchanges between CCI-E and members and highlighted again their tremendous work to support, with many means, children with cancer and their families.

This is also the first experience for CCI-E that such a traumatic long-lasting emergency impacted its members and community. Despite the challenges, this experience consolidated existing relationships between members and CCI-E, but also created new collaboration among members, committee and staff.

CCI-E aims to give every child and every adolescent a chance, and is also being fulfilled within the mission in SAFERUkraine.

ANNEX A

Financial Report

Donations		
Website donations	€30,330.68	
Bank transfer donations	€231,808.37	
	€262,139.05	
Family reunifications costs and funeral contribution		
		€11,323.71
Administrative Expenses		
Transfer Fees		€1,401.45
Travel and accommodation costs for SaferUkraine expert presentations and meetings		€1,046.02
Project Management		€46,340.03
		€60,111.21
Current balance as of December 31, 2022	€202,027.84	

Last Update: 31.12.2022

ANNEX B

Publications

Kaufmann, B. (May 2022). "Wir brauchen einander". *Wir, 13575*(2.22), S. 8-10. Von https://www.kinderkrebsstiftung.de/wp-content/uploads/2022/05/WIR_2_22.pdf abgerufen

https://cancerworld.net/unicorns-for-ukraine-mobilising-to-meet-patients-changing-cancer-careneeds/

Agulnik, A., Avula, M. et al. (September 2022). "Global effort to evacuate Ukrainian children with cancer and blood disorders who have been affected by war", *The Lancet Haematology*, Volume 9, Issue 9, e645 - e647 https://doi.org/10.1016/S2352-3026(22)00259-9